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The Interfamilial Principle and the Harvest Festival

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Abstract

It is widely accepted that younger children can act as saviour siblings by donating cord blood or bone marrow to their gravely-ill brothers or sisters. However, it is under dispute whether these procedures are in the best interests of the child. This article suggests that parents may be relying on a thinly-veiled interfamilial approach, where the wider benefit to the whole family is used to justify the procedure to the Human Tissue Authority in the United Kingdom. This article suggests that the merging of familial interests to validate a non-therapeutic bone marrow harvest on a child forces altruism in a patient too young to understand, rendering the harvests unlawful under current law.

Keywords

interfamilial principle – saviour siblings – Human Tissue Authority – bone marrow donation – minors

1 Introduction

The law on saviour siblings in the United Kingdom starts and ends with one case: *Re Y* (*Mental Patient: Bone Marrow Donation*) [1997] Fam. 110. Connell J confirmed that in the absence of a physical benefit a donor must glean some kind of psychological benefit from a bone marrow donation for her best interests to be met. The donor in *Re Y* was an incompetent adult who had very little

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awareness of the world around her, so the court used what appeared to be an interfamilial approach, relying on a probable improvement in the wider family unit to validate the harvest.

The Human Tissue Authority has published guidelines — Code of Practice 6: Donation of Allogeneic Bone Marrow and Peripheral Blood Stem Cells for Transplantation (2014) — on the harvest of bone marrow from very young children and incompetent adults.[1] It has the power to approve the procedure as being in the best interests of the child under the Human Tissue Act 2004 and the Human Tissue (Quality and Safety for Human Application) Regulations 2007.[2] The idea that a child could be harvested on the basis of wider benefits to family members should be urgently examined in light of the following statistics provided by the HT Authority (see Table 1).

TABLE 1 *Statistics from the human tissue authority*[3]

Year	Child bone marrow/ blood stem cell cases approved	Cases rejected
2007-2008	71	0
2008-2009	57	0
2009-2010	78	0
2010-2011	67	0
2011-2012	68	0
2012-2013	69	0
2013-2014	78	0

1 Code of Practice 6: Donation of Allogeneic Bone Marrow and Peripheral Blood Stem Cells for Transplantation, (2014); Human Tissue Authority, www.hta.gov.uk. *Gillick* competent children can issue their own consent: *Gillick* v. *West Norfolk and Wisbech Area Health Authority* [1986] AC 112, per Lord Scarman, pp. 188-189.

2 Code of Practice, paras. 27, 65 and 107. The approval process is also described in clear detail under paras. 28, 30 and 31.

3 These statistics were requested from the Human Tissue Authority by the writer under the Data Protection Act in January 2015 and delivered via email.

The consistent zero in the 'cases rejected' column is a cause for concern, and combined with the distress of the parents at the point of consent it is feared that objectivity may have been lost in the donation process.

This article focuses strictly on the interfamilial principle and its potential application to very young saviour siblings. It will conclude that a familial approach to best interests conflicts with the notion of paramountancy under the Children Act 1989 rendering the harvest of her bone marrow unlawful under current law.[4]

2 Re *Y* (*Mental Patient: Bone Marrow Donation*) [1997] Fam. 110

The House of Lords judgment in *Quintavalle* v. *Human Fertilisation and Embryology Authority* (*and Secretary of State for Health*) [2005] 2 A.C. 561 confirmed that a saviour sibling can be created during fertility treatment using Preimplantation Tissue Typing (PTT) in accordance with the desires of the mother.[5] The law under the Human Fertilisation and Embryology Act 1990 was changed to allow this to happen under schedule 2, paragraph 1ZA(1)(d). However, just because the law has authorised the *creation* of saviour siblings during fertility treatment (or the child is conceived naturally), it does not mean that the newly born child can be legitimately *harvested* for its bone marrow in law. The trespass to her body will only be lawful if a tangible therapeutic benefit (physical or psychological) can be found in herself to exist.

Re Y (*Mental Patient: Bone Marrow Donation*) [1997] Fam. 110 was a strange moment in law. It was the first clear confirmation that an invasive medical procedure could be performed upon an incompetent adult patient with no direct therapeutic benefit.[6] Connell J found that the incompetent adult donor (Y) was severely handicapped and did not know that her older sister was sick. She only had a trifling connection to her mother.[7] There was clearly no *physical* therapeutic benefit to Y to undergo a bone marrow harvest, but more importantly,

4 The welfare of the saviour sibling in regards to section 13(5) of the Human Fertilisation and Embryology Act 1990 and the inherent jurisdiction of wardship has been canvassed elsewhere: L. Cherkassky, 'The Wrong Harvest: The Law on Saviour Siblings', *The International Journal of Law, Policy and Family* 1 (2015) 1-20.

5 Per Lord Hoffman at paras.14, 22 and 24; Lord Brown at para. 62.

6 It has long been established that the interests of a child are influenced by the wider interests of the family, but in the context of non-therapeutic medical procedures on incompetent adults, a general benefit to the whole family was a new idea.

7 At pp. 112 and 115.

there was no obvious *psychological* benefit either because of her lack of understanding of the world around her.

In the United States, *Curran* v. *Bosze* (1990) 566 N.E.2d 1319 established that a bone marrow harvest upon a young child must satisfy the following three requirements:

1. the consenting parent must understand the risks and benefits of the procedure;
2. there must be emotional support from the person with parental responsibility;
3. there must be an existing close relationship between the donor and the sick child.[8]

The *Curran* judgment may have been geared towards child donors, but Connell J took inspiration from the third prong of the test, and validated the harvest in *Re Y* on the grounds that there were enough familial connections between the mother, sister and donor combined to manufacture a general emotional, psychological and social benefit to Y:

> In this situation, the [donor] would clearly be harmed by the reduction in or loss of contact with her mother. Accordingly, it is to the benefit of the [donor] that she should act as donor to her sister, because in this way her positive relationship with her mother is most likely to be prolonged. Further, if the transplant occurs, this is likely to improve the [donor's] relationship with her mother who in her heart clearly wishes it to take place and also to improve her relationship with the plaintiff who will be eternally grateful to her . . . it is relevant to ask the question, why subject the [donor] to this process? To this the answer, in my judgment . . . is because it is to her emotional, psychological and social benefit.[9]

The decision in *Re Y* requires justification. Firstly, the incompetent adult donor (Y) was barely aware of who her mother was, making the likelihood that she would benefit from her continued visits highly doubtful (i.e., these could have easily been replaced by a social worker or a carer). Calvo J made it very clear in *Curran* that there must be an existing close relationship between the *donor*

8 Per Calvo J, pp. 1343-1344. Calvo J did not approve the harvest, and the child in this case died.

9 [1997] Fam. 110, pp. 115-116. This was supported by writers including: R. Bailey-Harris, *Re Y* (*Mental Incapacity: Bone Marrow Transplant*) [1996] 2 FLR 787 (case note) in [1997] Fam. Law. 91, at p. 92.

and the recipient for a psychological benefit to 'realistically be found to exist'.[10] Secondly, the judgment in *Re Y* appeared to focus more on the wellbeing of the mother rather than the donor herself, who it was predicted. would *die* should the donation not go ahead.[11] In conclusion, *Re Y* did not correctly follow the guidance in *Curran* v. *Bosze* and stepped out on its own, generating a new concept of interfamilial interests. The requirement for a direct benefit between close siblings is substituted for a general familial benefit focusing not on the donor at the centre of the action but the plight of family members. This is the crux of the interfamilial principle, whereby the interests of the whole family are thrown into one melting pot and the needs of third parties override, subsume, dictate, influence or merge with the best interests of the donor. There is room for this to happen in the best interests test for incompetent adults (first designed in *Re F* (*Mental Patient: Sterilisation*) [1990] 2 AC 1) because the common law can be interpreted as widely or as narrowly as is necessary, but in regards to children only the child is paramount under the Children Act 1989 (explored below) leaving no room for manoeuvre.[12] *Re Y* and the principle therein should not be applied to child donors.

Disappointingly, the ethos of the decision in *Re Y* appears to feature in the Human Tissue Authority guidelines on child donation:

> Paragraph 82: A person with parental responsibility can consent to storage and use of bone marrow for transplantation on behalf of the child, if the donation is assessed as being in the child's *overall best interests*, taking into account not only the medical but also *emotional, psychological and social aspects* of the donation, as well as the risks.[13]

The influence of *Re Y* on the Human Tissue Authority guidelines means that parents of saviour siblings can place a selection of wider familial/social interests on the table to help sway the decision in favour of harvest. These could include: 'the siblings would have each other to play with', 'they would support

10 (1990) 566 N.E.2d 1319, pp. 1343-4.

11 [1997] Fam. 110, pp. 112, 113 and 115.

12 Rather tellingly, *Re Y* has been considered by only one appeal case and mentioned by only five others since its decision in 1997: *R* v. *HFEA ex parte Blood* [1999] Fam. 151; *St George's Healthcare NHS Trust* v. *S* [1998] 3 W.L.R. 936; *R* v. *HFEA* [2003] EWCA Civ. 667; *HL* v. *United Kingdom* (2005) 40 E.H.R.R. 32; *S* v. *Rochdale MBC* [2008] EWHC 3283 (Fam.) and *A NHS Trust* v. *DE* [2013] EWHC 2562 (Fam.).

13 Code of Practice 6: Donation of Allogeneic Bone Marrow and Peripheral Blood Stem Cells for Transplantation, (2014), Human Tissue Authority, www.hta.gov.uk, emphasis added.

each other throughout life', 'we would be a complete family unit' or 'none of us want to experience the death of a family member'. There is no doubt that these propositions are felt by the parents but they are merely speculative for a newly born or toddling donor.

The Human Tissue Authority may be adopting the interfamilial approach to be fairer to the family unit as a whole, but would it be legally acceptable to validate a trespass to the child in this way? It is time to explore the interfamilial principle to see how it aligns with the current legal principles of welfare as a potential approach for validating a bone marrow harvest on a very young donor.

3 The Interfamilial Principle and Its Application to Saviour Siblings

A saviour sibling is likely to be harvested for bone marrow when it is very young, perhaps days or weeks after birth depending on how sick the older sibling is (especially if it was conceived via fertility treatment for this purpose). There are three potential psychological benefits available to a donor child to satisfy her best interests in law. The first one takes the form of treats or rewards, but these are specifically excluded from the donation process by the Human Tissue Authority Code of Practice:

> Paragraph 28: Before the HT Authority can approve such cases, the regulations require that the HT Authority must be satisfied that:
>
> (i) no reward has been, or is to be, given.
>
> Paragraph 87: Deciding what constitutes reward or coercion can be a difficult judgment to make, and these issues should be explored thoroughly by Accredited Assessor's within interviews.
>
> Paragraph 88: Children are often given treats to compensate for an unpleasant experience, such as going into hospital or undergoing a painful procedure, and the form of treat is likely to vary considerably between different families and different cultures. However, some types of treat may be sufficiently desirable that there is a risk that they could induce the child to donate.
>
> Paragraph 90: If there is any doubt about whether the child is donating because of the promise of a reward, or the child is being coerced to donate through any other means, the AA should seek guidance from other Accredited Assessor's, and raise their concerns within their report to the HT Authority.

The second type of psychological benefit could be an emotional one, such as a feeling of pride, altruism or happiness at being able to help a family member. This higher level of thinking is usually associated with adults who donate bone marrow or kidneys, not babies or toddlers or very young children.

Writers have suggested a third type of psychological benefit — a 'general completeness' in the family unit otherwise known as the interfamilial approach — where the needs of the wider family are incorporated into the best interests test. Its main aim is to ensure that the wider interests of the family are met. The legal question is, should a transplant team be able to perform an invasive procedure on a child simply because it offers an immediate benefit to the wider family? The Human Tissue Authority guidelines on donation clearly state that in the event of a disagreement on best interests, the jurisdiction of the High Court should be sought:

> Paragraph 107: Where a child is a potential bone marrow donor and not competent to consent, a person with parental responsibility can consent to donation on behalf of the child if the donation is assessed as being in the child's overall best interests. However, where there is a dispute between persons with parental responsibility, or between them and the clinicians looking after the child, or there is a doubt as to best interests, the court should be asked to rule in advance.
> Paragraph 109: If the court is asked to consider the matter, the welfare of the prospective donor child will be the court's paramount consideration and not the welfare of the recipient. The 'welfare checklist' which is set out in the Children Act 1989 will be considered by the court in determining the application.[14]

These are important provisions because they provide objectivity in a situation where emotions run very high. The welfare test under section 1(1) of the Children Act 1989 states that with respect to the upbringing of the child, the child's welfare is the paramount consideration. Relevant factors under section 1(3) include his wishes and feelings, physical and emotional needs, the effect on him of any change, his age, sex and background, any harm he is at risk of suffering, and the capabilities of his parents to meet his needs. In the event that the welfare test is applied to a child donor (which has not happened in a

14 Code of Practice 6, *ibid*. It can be inferred from these paragraphs that if the parents do not disagree, the HT Authority will use its full discretion without any legal interference.

high profile case yet), the common law has already provided strong hints that an interfamilial approach would not be well received. The possibilities can be split into three sub-categories: (i) subsuming the rights of the child into the rights of the parents; (ii) a melting pot of familial interests; and (iii) a balancing act between siblings. The common law has ruled on these wider approaches to welfare in other child cases and has rejected every single one, because they do not support the paramountancy of the child.

3.1 *Subsuming the Rights of the Child*

Parents of saviour siblings are in a very difficult position. They have to harm one child to save their other child. Parental consent is not often questioned because there is an assumption that the proposed medical procedure is in the best interests of the child. Bone marrow harvests are different, because a psychological benefit must be proven to justify the trespass to the child and this is incredibly difficult to do in very young children, leaving parents free to instil their own altruistic ideals into the newly born or toddling child in the hope that this will constitute the required benefit. There is some support for this approach. Ross, for example, believes that the autonomy of the child should be subsumed into the autonomy of the parents for the interests of the wider family:

> . . . if the organ is donated to another family member, then the child is advancing the family's own interests, which is a means to promoting the child's own interests. . . . although a child who is asked to serve as a donor may dissent because he fears the physical pain, the parents must have the power to override his narrow self-interest for the wellbeing of his sibling and the family as a whole . . . family autonomy warrants, indeed requires, this discretionary freedom.[15]

These comments may be unhelpful. Firstly, it is dangerous to suggest that parents should be exempt from the welfare test so they can raise their family according to their own vision — there are a small handful of families who have negligent and frankly dangerous visions for their children, highlighting the need for an objective test in welfare cases. Secondly, paramountancy is not a "narrow self-interest"; it is a vital tool to ensure the national and international rights of the child. To completely subsume the autonomy of the child

15 L.F. Ross, 'Moral Grounding for the Participation of Children as Organ Donors', *Journal of Law, Medicine and Ethics* 21 (1993) 251, pp. 253, 254 and 255. Also see: L.F. Ross, 'Justice For Children: The Child as Organ Donor', *Bioethics* 8(2) (1994) 105, pp. 110, 114, 115, 118 and 119.

would mean a substitution of her rights for those of the wider family and her autonomy and bodily integrity would be lost.

In this respect, the interfamilial principle could allow altruism to be portrayed through the child on behalf of the parents, almost like a substituted judgment.[16] The concept of forced altruism and its effects have been discussed in the literature on saviour siblings and it becomes clear that altruism is a higher mind-set that cannot be enforced upon a young child, per Glannon:

> Altruism is the "willingness to act in consideration of the interests of persons, without the need of ulterior motives" [and] "a regard for the good of another person for his own sake, or conduct motivated by such a regard". As an altruistic act, organ donation is not a *quid pro quo*; one does not do it on the condition that one will receive some psychological benefit in return. What makes these acts laudable or praiseworthy is that they are freely chosen at some cost or risk of harm to oneself and are directed at individuals to whom one stands in no special relationship.[17]

Crouch and Elliott agree that altruism is simply not in the nature of young children:

> . . . if the donor is not mentally developed to a sufficient degree, he will not only fail to understand why he is in the hospital and why he has been physically harmed, he will also fail to understand the important role that he has played in the care of his sibling. Thus he may well not receive any psychological benefits as a result of his donation.[18]

Altruism is a psychological benefit that could fulfil the best interests test for adult donors (and perhaps *Gillick* competent children) because they are capable of acquiring it, but it is clear that a baby or toddler cannot donate bone marrow altruistically. The idea put forward by Ross that parents should override the rights of the child to promote good Samaritanism may simply be a strategy to instil their own altruistic ideals into their child. Griner speaks of

16 The concept of substituted judgment and parents of saviour siblings has been canvassed elsewhere: L. Cherkassky, 'Children and the Doctrine of Substituted Judgment', *Medical Law International* 1 (2015) 1-23.

17 A. Glannon and L.F. Ross, 'Do Genetic Relationships Create Moral Obligations in Organ Transplantation?', *Cambridge Quarterly of Healthcare Ethics* 11 (2002) 153, pp. 153 and 154.

18 R. Crouch and C. Elliott, 'Moral Agency and the Family: The Case of Living Related Organ Transplantation', *Cambridge Quarterly of Healthcare Ethics* 8 (1999) 275, at p. 282.

a compulsion by the parents to force their priorities and responsibilities upon the donor child:

> The parent-child relationship is not the same as a sibling relationship. While a parent may feel obliged to donate an organ to a child, a sibling may not necessarily feel the same compulsion. This is especially true when the siblings are very young and may only be able to appreciate the familial relationship in its most rudimentary aspects. The balancing test then becomes a matter of imposing the parent's view of familial obligation on the child who may have a different set of priorities and responsibilities.[19]

Ladd agrees that 'parental consent without child assent would amount to requiring of a child a degree of altruism that we do not ever require of adults'.[20] Altruism was discussed in *Curran* v. *Bosze* 566 N.E.2d 1319 (1990) and Calvo J believed that it could be as much as twenty years before the psychological benefits of a bone marrow donation are felt by the donor child.[21] He also suggested that altruism should be present *at the time of the harvest* as a motivating factor — not in future to retrospectively justify the harvest — and that motivation and intention could not be supplied after the fact.[22] A definitive passage by Wilson J in *Re C* (*A Child*) (*HIV Test*) [2000] Fam. 48, however, removed any doubt as to the rights of the parents to subsume the rights of their child into their own when he stated that 'if the father regards the rights of a tiny baby as subsumed within the rights of the parents, he is wrong. This baby has rights of her own. They can be considered nationally or internationally'.[23] The High Court plays the role of the reasonable parent in difficult medical cases. The wishes of the parents to either be included in deliberations of welfare, to subsume the rights of their child into their own or to instil their own altruistic ideals into the child are rejected in favour of the welfare of the child under s.1(3) of the Children Act 1989 no matter how grave the circumstances are,

19 R.W. Griner, 'Live Organ Donations Between Siblings and the Best Interest Standard: Time for Stricter Judicial Intervention', *Georgia State University Law Review* 10 (1994) 589, at p. 603.

20 R.E. Ladd, 'The Child as Living Donor: Parental Consent and Child Assent', *Cambridge Quarterly of Healthcare Ethics* 13 (2004) 143, pp. 146-147.

21 At p. 1335. The benefit was not to be 'one of personal, individual altruism in an abstract, theoretical sense' at p. 1343.

22 *Ibid*., p. 1336.

23 At page 61.

rendering this subcategory of the interfamilial principle invalid. It is often disappointing for parents to learn that their views have no influence on the welfare test but if, in a child bone marrow donation case, the judge found it to be in the best interests of the child to donate bone marrow to her older sibling, the decision would have had nothing to do with her parents. Judges can choose to listen to and consider their views, but nothing more.

3.2 *A Melting Pot of Familial Interests*

The second subcategory of the interfamilial principle is probably the most common, supporting a long and thin psychological benefit spread over the whole family unit as opposed to a single benefit to the donor child. This benefit is phrased in typically emotive terms, such as "the whole family would benefit from having both children alive and well". The avoidance of death is also found under this subcategory, where parents may argue that the act of harvest prevents the saviour sibling from suffering the grief of loss. The Human Fertilisation and Embryology Authority has adopted this approach by incorporating the grief of loss into its Preimplantation Tissue Typing guidelines: 'if a medical procedure, such as a bone marrow transplant, would save the life of a sibling, it is likely to be in the best interests of the child, since to lose a sibling is psychologically damaging'.[24] The decision in *Re Y* also hinged on the avoidance of death and its decision was supported by writers.[25] A direct avoidance of death can be seen in one of the oldest saviour sibling cases in the U.S. named *Masden* v. *Harrison* No.68651 Eq., Massachusetts, 12 June 1957.[26] The kidney donation was validated on the grounds that the death of the sick brother would have a negative psychological impact on the donor.[27]

The decisions in *Re Y* and *Masden* v. *Harrison* involved older donors, so the death of the sick sibling may have had some kind of psychological effect, but it would be pure speculation to say that a newly born or toddling donor will be effected by the same event because they have no understanding of

24 Human Fertilisation and Embryology Authority Report, 'Preimplantation Tissue Typing', (2004), Human Fertilisation and Embryology Authority, http://www.hfea.gov.uk, at para. 25.

25 L.A. Jansen, 'Child Organ Donation, Family Autonomy, and Intimate Attachments', *Cambridge Quarterly of Healthcare Ethics* 13 (2004) 133, pp. 139-140; S. Sheldon and S. Wilkinson, 'Hashmi and Whitaker: An Unjustifiable and Misguided Distinction?', *Medical Law Review* 12(2) (2004) 137, at p. 142.

26 A kidney donation was required between twins (aged 19). They were both competent, but the age of majority was 21. The parents could not consent to the procedure in law either, so the court had to ponder an alternative avenue to consent.

27 Crouch and Elliott, *supra* note 18, at p. 278.

mortality. There will certainly be an appreciation of a gap in the family tree in future years, but this is the case in every family — death cannot be postponed. A dissenting judge in another old U.S. case on donation — S*trunk* v. *Strunk* (1969) 445 S.W. 2d 145 Ky. — came to the conclusion that: 'the loss of a close relative or a friend to a six-year old child is not of a major import'.[28] Parents could not argue, therefore, that a bone marrow harvest would prevent grief in the donor child because it is purely conjectural.

It is naïve, of course, to believe that the death of an older sibling would not have *any* effect on a younger sibling. The wording of the welfare test does state:

> (c) the likely effect on him of any change in his circumstances,
> (d) his age, sex, background and any characteristics of which the court considers relevant.

Might there be room for the natural death of a family member to be incorporated into the welfare test as a *change in circumstances* or a *characteristic* that could have a negative effect on the donor child? It is suggested that paragraphs (c) and (d) are more likely to refer to physical and psychological changes resulting from a legal decision such as removal into foster care. The inclusion of a family illness into the welfare test would be unfair to the saviour sibling if he was a potential cure for the illness, because the court would feel obliged to validate the harvest on the grounds that it would be for his own good to regard him as a treatment to be administered. The welfare test would turn into a vehicle for the harvesting of children for bone marrow.

This leads us on to an additional complication: awareness. The donor child must have awareness of a psychological benefit for it to manifest. The interfamilial principle attempts to plug this gap by stretching the psychological benefit far and wide. The Children Act 1989 does not comment on awareness but does mention the child's age: 'Section 1(3)(a) the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding)'.

In a case of bone marrow harvest, a younger child would only have a rudimentary understanding of the procedure compared to an older child. *Re A* (*Male Sterilisation*) [2000] 1 F.L.R. 549 confirmed that when deliberating best interests the case 'must be proved'.[29] This suggests a tangible — not a speculative — physical or psychological benefit and it is impossible for a child donor to derive such a benefit if he has no knowledge of it. The suggestion that she

28 At p. 150.

29 Per Butler-Sloss L.J. at p. 555.

would simply benefit from 'having a sibling around' or 'having a complete family' is not enough according to Calvo J in *Curran* v. *Bosze* (1990) 566 N.E.2d 1319:

> It is not in the best interest of either Allison or James [the twins] to undergo the proposed bone marrow harvesting procedure. . . it is not possible to discover the child's likely treatment/non-treatment preferences by examining the child's philosophical, religious and moral views, life goals, values about the purpose of life and the way it should be lived, and attitudes toward sickness, medical procedures, suffering and death . . . at the age of three and a half, it is very difficult if not impossible to predict what a specific individual will do in a specific circumstance at a specific point of time in the future.[30]

There are plenty of medical cases (U.K. and U.S.) to confirm that patient awareness and best interests are tied together, including *Strunk* v. *Strunk* (1969) 445 S. W. 2d 145 Ky, *Hart* v. *Brown* (1972) 289 A. 2d 386, Conn. Super Ct. and *Little* v. *Little* (1979) 576 S. W. 2d 493 Tex. for the U.S. (donation cases), and *Re B* (*A Minor*) (*Wardship: Sterilisation*) [1988] A.C. 199, *Re F* (*Mental Patient: Sterilisation*) [1990] 2 A.C. 1, *Airedale NHS Trust* v. *Bland* [1993] A.C. 789, *Re A* (*Male Sterilisation*) [2000] 1 F.L.R. 549 and *An NHS Trust* v. *MB* [2006] EWHC 507 for the U.K. (welfare cases). The High Court in the UK has not, so far, validated a non-therapeutic medical procedure on a child for purely speculative psychological reasons such as 'she can share her life with her sibling' or 'she will be so much happier in the future knowing that she donated'. In light of the Human Tissue Authority statistics above, does this mean that awareness of a psychological benefit has been found in every single child donor case since records began in 2007?

The wishes of the parents to spread the required psychological benefit far and wide across the family unit to constitute the best interests of the child is rejected under the common law. It would also be unacceptable to suggest that the prevention of the death of a family member is enough justification to trespass upon a child in an invasive manner.[31] The saviour sibling must clearly glean her own tangible psychological benefit from the bone marrow harvest and awareness of that benefit is vital for it to manifest. A strong relationship

30 Per Calvo J, pp. 1343, 1344, 1319, 1326 and 1336. Bosze argued in response that if Jean Pierre was kept alive, the twins would have the opportunity to get to know him. This speculative future benefit did not hold any weight in court.

31 *Re A* (*Children*) (*Conjoined Twins: Surgical Separation*) [2001] Fam. 147 is distinguishable on the grounds that if no surgery was authorised, both children would have died.

with the sick sibling appears to be good evidence of this. The only avenue left for parents who wish to use the interfamilial principle to validate a bone marrow harvest upon their young child is the potential balancing of interests between the sick and the saviour sibling.

3.3 *Balancing Act between Siblings*

Re Y took the 'balancing exercise' approach. A more interesting perspective is that of Pennings, who suggests that a balancing act will ensure that the *sick* child is not neglected:

> The relationship between donor and recipient functions in an indirect way: it explains why the donor has an interest in the wellbeing of the recipient. To the extent that the wellbeing of the others is part of one's own wellbeing, the person is helping himself. In fact, it can be argued that refusing this use (e.g. not agreeing to the bone marrow donation of one child if there is a serious chance that its sibling can be saved) would be an unacceptable neglect of the sick child's interests. Being informed of the fact that you were conceived to help your sibling may give a greater sense of self-esteem and self-worth . . . compared with most other persons, who are conceived by accident or without any conscious thought at all, this child already has a reason to exist.[32]

It is debatable that the interests of the sick and the saviour child should be balanced against each other as they have different legal interests: the sick child seeks a right to life whereas the saviour child seeks protection from trespass to the person. Similarly, the harm to the saviour child (needles, anaesthetic) is unfairly overshadowed by the potential death of the sick child. Pennings has described the substantial burden on the donor child:

> It could be argued that a heavy burden is placed on the donor child. The transplantation may fail and this may give the child a fundamental sense of unworthiness and deficiency and a feeling of not being able to live up to the expectations.[33]

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32 G. Pennings, R. Schots and I. Liebaers. 'Ethical Considerations on Pre-Implantation Genetic Diagnosis for HLA Typing to Match a Future Child as a Donor of Haematopoietic Stem Cells to a Sibling', *Human Reproduction* 17(2) (2002) 534, pp. 536 and 537.

33 *Ibid.*, at pp. 537 and 538.

Jecker adds a catalogue of potential psychological harms to the saviour child:

> Children aren't medicine manufactured for other people. Conceiving children to benefit others violates a principle that should guide ethical decision making regarding becoming a parent; namely, doing what will be best from the potential child's point of view. [The donor] is likely to suffer psychological harm as a result of being conceived for the purpose of benefitting her sister. She might be prone in the future to regard her worth as conditional on the benefits she can provide others. She might harbour resentment toward her parents for choosing to conceive her for this purpose, or toward her sister for reaping benefits from her conception. These feelings could present formidable obstacles to living relationships within the family, and thereby handicap [the donor] in the future. Family relationships profoundly shape our relationships with persons outside the family circle, and they influence the kind of person we strive to become.[34]

There are far more burdens to the saviour child, including bone fracture, bone infection, rupture of an artery, skin scarring, hypertension, anaemia, broken needles, blood transfusion, pain, fear of operations, fear of losing a body part, spite, resentment, refusal, force, manipulation, exploitation, guilt, rejection and being treated as an insurance policy.[35] Delany goes one further and

34 N.S. Jecker, 'Conceiving a Child to Save a Child: Reproductive and Filial Ethics', *The Journal of Clinical Ethics* 1(2) (1990) 99, at p. 100.

35 Life threatening risks that have been reported in real cases include non-fatal cardiac arrest, pulmonary embolus, aspiration pneumonitis, ventricular tachycardia and cerebral infarction (connected to the general anaesthetic): M.M. Bortin and C.D. Buckner, 'Major Complications of Marrow Harvesting for Transplantation', *Experimental Hematology*, (11)(10) (1983) 916-921, at p. 919. For further discussion of bone marrow harvest risks see: J. Hunter, 'Consent for the Legally Incompetent Organ Donor', *Journal of Legal Medicine* 12(4) (1991) 535; Griner, *supra* note 19, 589; S. Holm, 'The Child as Organ and Tissue Donor: Discussions in the Danish Council of Ethics', *Cambridge Quarterly of Healthcare Ethics* 13 (2004) 156; A. Spital, 'Donor Benefit Is the Key to Justified Living Organ Donation', *Cambridge Quarterly of Healthcare Ethics*, 13 (2004) 105; S. Zinner, 'Cognitive Development and Paediatric Consent to Organ Donation', *Cambridge Quarterly of Healthcare Ethics* 13 (2004) 125; and L.F. Ross and J.R. Thistlethwaite Jr., 'Minors as Living Solid Organ Donors', *Paediatrics* 122 (2008) 454. For an alternative look at the risks to the *sick* child, see: http://www.chw.org/medical-care/macc-fund-center/conditions/hematology-and-blood-disorders/bone-marrow-transplantation, accessed on 31 March 2015.

suggests that a bone marrow harvest would be *against* the best interests of the donor child:

> It is by no means clear that harvesting bone marrow from a child is legal. Neither statute nor case law specifically sanctions bone marrow donation by a child. Adopted by the House of Lords in *Gillick* and consistent with the philosophy of the Children Act 1989, [one approach] permits a medical procedure only if it serves the best interests of the child who undergoes it. Assessments based on factors such as [tests, anaesthetic, pain, discomfort, pressure, fear and disapproval] may show that bone marrow donation is not "in the best interests" of the donor. Indeed, they may conclude that a donation is against the child's interests. When the proposed donor is too young to have established an emotional bond with the proposed recipient of the bone marrow the factors favouring the medical intervention appear to be outweighed by those against it.[36]

Unfortunately for parents of child donors the law has been very clear on the entangling of interests under the Children Act 1989 - the needs of other family members are excluded from the welfare test. This was confirmed in the following cases:

- *S v M* [1972] A.C. 24;
- *Re X* (*A Minor*) (*Wardship: Jurisdiction*) [1975] Fam. 47;
- *Re B* (*A Minor*) (*Wardship: Sterilisation*) [1988] A.C. 199;
- *Re A* (*Medical Treatment: Male Sterilisation*) [2000] 1 F.L.R. 549;
- *Re A* (*Children*) (*Conjoined Twins: Surgical Separation*) [2001] Fam. 147.

The common law is clear: the welfare test is not applicable to the sick sibling because his plight would cause unfair prejudice and domination. The only instance where siblings can be balanced against one another in a welfare test is when they are both warded at the same time:

- *Court of Appeal* [1993] 1 FLR 883;
- *Birmingham City Council* v. *H* (*A Minor*) [1994] 2 AC 212.

Should parents try to instigate a balancing exercise between the sick and the saviour child to suggest that the discomfort to one is outweighed by the benefit

36 L. Delany, 'Protecting Children from Forced Altruism: The Legal Approach', *British Medical Journal* 312 (1996) 240.2.

to the other it would grate against the principle of paramountancy under the Children Act 1989. It generates a grossly unfair advantage to the sick child whose illness is not the fault or problem of the saviour child. This detached attitude is difficult to accept, but the welfare test is designed to be strictly objective to ensure that the best interests of the warded child are paramount. The courts have already refused to measure the consequence of death as a result of *McKay* v. *Essex Area Health Authority* [1982] Q.B. 1166 when it was decided that a court cannot 'evaluate non-existence'.[37] A balancing act between family members plays no part in the welfare test under the Children Act 1989. There is no disputing that the interfamilial approach has the best interests of both siblings at heart, but the autonomy of the donor child would have to be swallowed up to allow her to be used as a commodity to provide immediate relief to the sick child. It is highly unlikely that the welfare test under s.1 of the Children Act 1989 was designed to be used as a vehicle for medical treatment in this way.

Overall, it is clear that despite the plight of the sick sibling, the High Court, when applying the welfare test under s.1(3) of the Children Act 1989:

- will not allow parents to subsume the rights of the child into their own,
- will not allow parents to force the child to behave altruistically,
- will ensure that the child is aware of a psychological benefit to validate the harvest in law,
- will make sure that the benefit is not social in nature or spread thinly throughout the family, and
- will not allow the plight of the sick sibling to be balanced against the discomfort of the saviour sibling unless both are warded at the same time.

In conclusion, the interfamilial principle as a tool to validate a medical procedure on a child has been widely avoided by the courts and would not necessarily render a non-therapeutic bone marrow harvest upon a non-competent child lawful. The important question left to answer is why the Human Tissue Authority places significant weight upon parental consent and social factors to validate such a procedure at its discretion when the case law on medical treatments clearly rejects the familial approach to welfare in the event that no benefit can be found.

37 Per Lord Ackner, at p.1189. This case confirmed that there is no duty in law to ensure that a person does not exist (or to put it more accurately, there is no duty in law to perform an abortion). The U.S. courts came to the same conclusion in *Gleitman* v. *Cosgrove* 227 A.2d 689 (N.J. 1967).

4 Conclusion

A difficult case for the Human Tissue Authority would be the harvest of a newly born child created using PTT under the Human Fertilisation and Embryology Act 1990. The distress of these parents would be intolerable if they were to be turned away at the last hurdle, having gone through a gruelling fertility treatment process only to find that the harvest is not lawful. This loophole was ignored in *Quintavalle*, but just because the HFE Act 1990 made the creation of saviour siblings legal under schedule 2 paragraph 1ZA(1)(d) it does not mean that the harvest of bone marrow is legal. This also applies to saviour siblings conceived naturally too.

The fragments of law already existing clearly state that the donor child must be *aware* of a close existing relationship to her sibling to derive a benefit from donation (*Curran* & *Re Y*), this benefit must be *proven* (*Re A*), and only the interests of the donor child are paramount (1989 Act). The avenue used so far by parents and the Human Tissue Authority — the interfamilial approach — does not correspond with the law.

The need for objectivity in the donation is significantly increased when children are involved because the procedure hinges on parental consent, turning the donation into a 'family favour' as opposed to a medical procedure. Lord Hoffman in *Quintavalle* assumed that once born the saviour sibling would be able to rely on the law for protection: 'the [HFE] authority is in my opinion entitled to assume that a child conceived pursuant to its licence will, after birth, receive the full protection of the law'.[38] There was no further elaboration on this point, but if he was referring to wardship it has not yet been invoked. The sense that the saviour sibling is simply being used as a commodity is very strong. It does not help that our only authority on sibling donation — *Re Y* (*Mental Patient: Bone Marrow Donation*) [1997] Fam. 110 — adopted the interfamilial approach and merged the interests of the mother (who was frail) and the sick sibling (who had no relationship to the donor) with the incompetent donor to ensure that a psychological benefit was constructed. This decision should not have been incorporated into the Human Tissue Authority guidelines on bone marrow donations for children because the welfare test for children is very strict.[39] How does the Human Tissue Authority know that the objective best interests of the child donor are met when the welfare test under s.1 of the Children Act 1989 is only referred to in the event of a parental

38 *R* (*Quintavalle*) v. *Human Fertilisation and Embryology Authority* (*and Secretary of State for Health*) [2005] 2 A.C. 561, at para. 38.

39 At para. 78.

disagreement?[40] In light of the (relatively) small number of bone marrow donations from children every year, could it be possible to seek court consent in *every* case to ensure that the welfare of every donor child is met? It appears that the needs of the donor child are currently trumped by the needs of third parties which is the very threat the welfare test was designed to prevent.

40 At paras. 107 and 109 of the Code of Practice, *supra* note 13.